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# Perceptions of Gain Following Spinal Cord Injury: A Qualitative Analysis

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**Background:** Significant research has focused on psychological difficulties following spinal cord injury (SCI), and there is a small prevalence of individuals who experience distress after injury. However, the converse is that many adjust well to injury and rate their quality of life highly. Despite this, there has been a comparative dearth of research investigating positive psychological outcomes after SCI, perceived by individuals living with this disability. **Objective:** To explore individuals' perceptions of gain following the experience of SCI. **Methods:** Participants, who had sustained an SCI between the ages 16 and 83, responded to an open-ended written question: "What do you think you have gained from the experience of spinal cord injury?" This was administered at 4 time points post injury: 6 weeks, 12 weeks, 1 year, and 2 years. **Results:** Participants' responses were analyzed qualitatively using the framework of thematic analysis. Thirteen themes were identified: relationships, appreciation of relationships, perspective and appreciation of life, new goals or priorities, understanding of SCI or disability, appreciation of health or health care, changed personality, opportunity or challenge, knowledge of SCI or body, newly acquired skills, spirituality, acceptance, and nothing. Descriptive statistics were incorporated in the presentation of the data. **Conclusions:** This study provides evidence that a broad range of positive as well as negative psychological outcomes are possible following SCI. More research is needed to better understand the process through which these outcomes arise and to inform how such outcomes may be communicated to persons experiencing this type of injury. **Key words:** benefit-finding, gains, positive outcomes, posttraumatic growth, qualitative, spinal cord injury

Spinal cord injury (SCI) is a major trauma and can have a wide-ranging impact on an individual's life. Among the potential consequences of the injury is impaired physical, social, and psychological functioning.<sup>1</sup> It is thought that approximately 30% of spinal cord-injured individuals experience depression while in rehabilitation and 27% experience depression in the community.<sup>2</sup> Elevated symptoms of anxiety are also found in this population.<sup>2</sup>

Significant research has focused on psychological difficulties following SCI in order to inform theory and practice. However, as the above statistics reflect, not all individuals sustaining SCI experience negative psychological outcomes. Research consistently demonstrates that many people adjust well after SCI,<sup>3</sup> with 75% of people in one study stating that their present quality of life is good or excellent 20 years post SCI and that overall their health is good.<sup>4</sup> Despite these promising findings, there has been a dearth of research investigating the positive psychological

sequelae of SCI perceived by individuals who have experienced this disability.

There are several theoretical frameworks that are used to better understand psychological outcomes following a highly stressful life event, such as SCI. According to the Cognitive Model of Stress and Coping,<sup>5,6</sup> an individual makes 2 types of appraisals after experiencing such an event: primary appraisals involve an assessment about whether the event is a threat, a challenge, or harmless; and secondary appraisals involve an examination of the personal resources an individual possesses to deal with the event. The initial appraisals that a person makes influence the coping strategies that they use and can affect psychological outcome.<sup>7</sup> Kennedy and Duff have adapted this model to address aspects of adjustment and coping specific to SCI.<sup>8</sup>

Another theoretical framework from which to conceptualize the positive outcomes following SCI is psychological growth, variously called posttraumatic growth (PTG), benefit-finding, or adversarial growth. It is defined as an individual's perception of a positive self-transformation, which could be related to a variety of domains, and occurs as a result of the struggles associated with experiencing a catastrophic life event.<sup>9</sup> The experience of personal growth has long been observed clinically<sup>10</sup> and has been reported by individuals who have suffered a wide range of traumatic events.<sup>9,11</sup>

There are 3 domains in which positive changes are most commonly reported following the experience of adversity. First, there is a changed perception of self, which can make the person more vulnerable or more independent in coping with the challenges of life. Second, there is a changed perception of relationships, for example, enhanced closeness, emotions, and understanding of others. Third, there is a changed perspective of life, such as altered priorities, wisdom, and spirituality.<sup>12</sup>

Hefferon and colleagues<sup>13</sup> reviewed the qualitative literature on PTG for individuals who had been diagnosed with a life-threatening physical illness. They found several key themes of PTG across studies: *reappraisal of life and priorities*, *trauma equals development of self*, *existential re-evaluation*, and *a new awareness of the body*.

PTG after SCI has been investigated, but there is limited literature in this field. McMillen and Cook<sup>14</sup> used the Perceived Benefit Scales to quantitatively examine the positive outcomes of SCI at 18 to 36 months postinjury. A large number of individuals reported that they had experienced an enhanced sense of compassion and closeness to family members since their injury. They also reported consuming less alcohol after injury. However, the researchers questioned the validity of these outcomes, because of the subjective nature of self-report and because benefits in the relationships domain were not always concurrently perceived by family members.

Pollard and Kennedy<sup>7</sup> conducted a 10-year longitudinal study investigating emotional impact, coping strategies, and PTG following traumatic SCI. PTG was measured using the Posttraumatic Psychological Growth Inventory (PTGI).<sup>12</sup> A large

range in scores was observed, but the highest scores were found in the domains of personal strength and the lowest scores were for spirituality. The authors also found that the coping strategies of mental disengagement, depression, and active coping at 12 weeks accounted for 48% of the variance in self-reported PTG at 10 years postdischarge. These findings demonstrate a relationship between psychological distress and PTG.

Chun and Lee<sup>15</sup> investigated the characteristics of PTG after SCI through an exploration of the life narratives of 15 individuals before and after SCI, using qualitative methods (thematic analysis). The results indicated that 3 themes of growth were particularly pertinent: the experience of meaningful family relationships, engagement in meaningful activities, and an appreciation of life.

Most recently, Weitzner and colleagues<sup>16</sup> investigated individuals' perceptions of positive aspects that they had gained from SCI. Fifty-two participants were asked about ways in which they view and use their disability positively, and this was found to relate to 3 domains: self, peers, and disability community. *Self* referred to ways in which individuals felt that they had found benefit for themselves in their disability, such as self-advocacy, personal growth, new hobbies or opportunities, work, and benefits. The remaining 2 themes related to ways in which individuals felt that they used their SCI to benefit their peers or the community of other persons with disabilities. Several mediating factors were found to influence these perceived benefits: personal factors, social support, acceptance of the disability, and spirituality.

A better understanding of the positive outcomes that arise after SCI is important for informing clinical practice. Helping an individual to become aware of the positive outcomes that may have arisen from the experience of trauma may ameliorate self-esteem and self-efficacy<sup>17</sup> as well as overall health.<sup>18</sup> Moreover, re-appraisal coping, an intervention in which the meaning of the situation is reframed more positively, has been found to be related to PTG, positive psychological states, and coping.<sup>19</sup> Awareness of these effects may help in developing similar interventions to ameliorate positive appraisals and adjustment in people who are identified as being at risk for experiencing distress after SCI.

The present study contributes to the limited existing literature<sup>20</sup> and aims to explore the ways in which people perceive that they have benefitted positively from the experience of SCI. A qualitative methodology was used, as these methods allow a deeper investigation of subjective experience.<sup>21</sup>

## Method

### Participants

The total sample of the initial study that examined SCI rehabilitation over 2 years across Europe<sup>22</sup> was comprised of 232 participants who had sustained an SCI between the ages 16 and 83 and were admitted to specialist units in selected British ( $n = 100$ ) and German ( $n = 132$ ) SCI centers. The age range of participants was 18 to 74 years of age, and the majority were men. At 12 weeks, 184 (79.3%) men and 48 (20.7%) women participated; at 2 years post injury, 71 (78.9%) men and 19 (21.1%) women completed the questionnaire. Individuals were fluent in the language of the country from which they were recruited. Exclusion criteria were head injury or known communication disorder, as these may adversely affect the ability of an individual to comprehend and complete the study.

### Design

A qualitative, longitudinal multiwave panel design was used.

### Procedure

The data were collected as part of a large longitudinal multicenter study investigating coping and adjustment after SCI.<sup>22</sup> All participants gave their consent. At 4 time points post injury (6 weeks, 12 weeks, 1 year, and 2 years), participants were asked the open-ended question, "What do you think you have gained from the experience of your spinal cord injury?" Ethical approval for this study was obtained from each center's local research ethics committee. All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

### Data analysis

The principles of thematic analysis were used to analyze participants' responses.<sup>23</sup> Responses were read and re-read, and initial coding of prominent areas in which positive gains were reported was noted over a 9-month period. Definitions for emerging themes were formulated during this process and were supported with quotes from the data. This process was repeated, and links between themes were identified. Three independent researchers worked sequentially with some external triangulation, with at least 2 coders coding each response, until a final set of themes that most accurately represented the individuals' experiences was determined.

Once the data had been reviewed and theme categories created, the data were coded as follows: Whenever a response (or part of a response) related to a particular theme, a score of 1 was assigned to that theme for that time point. As there was no specification as to the amount of gains each participant could provide, each individual could contribute to the scores for more than 1 theme. However, for each response, a maximum score of 1 could be assigned to a particular theme regardless of how many times it was mentioned in the response.

## Results

### Response rates and demographics

Of the original sample of 232, 14 individuals from the German sample were excluded, either because they stated it was too early for them to answer the question or because their answers were not applicable. The number of individuals who responded at each time point was as follows: 6 weeks,  $n = 201$ ; 12 weeks,  $n = 159$ ; 1 year,  $n = 91$ ; and 2 years,  $n = 51$ . Paraplegic injuries accounted for 51.83% ( $n = 113$ ) of injuries, and tetraplegic injuries accounted for 47.71% ( $n = 104$ ) of injuries.

### Resulting themes

Thirteen themes were identified through thematic analysis, and the percentage of responses falling into each theme at each time point was

**Table 1.** Percentage of responses to the question “What do you think you have gained from the experience of your SCI?” according to theme and time point

Theme	Percentage of responses according to time point			
	6 Weeks	12 Weeks	1 Year	2 Years
Perspective/appreciation of life	27	24	24	31
Changed personality	13	12	13	17
Nothing	14	8	11	12
Understanding/perspective of disability/SCI	10	10	9	9
Appreciation of relationships	7	6	6	9
Knowledge of SCI body	6	11	8	1
Relationships	9	11	10	5
Changed goals/priorities	3	4	5	4
Opportunity/challenge	2	4	3	4
Acceptance of SCI/help	4	4	4	0
Appreciation of health/health care	2	2	3	4
Spirituality	1	2	2	3
Newly acquired skills	1	2	2	0

calculated; these are shown in **Table 1**. The percentages represent the percentage of people in the sample who at that time point gave a response that fit into that category.

The themes are outlined below with representative quotes taken from as broad a range of the sample as possible.

#### ***Perspective/appreciation of life***

Many people talked about gaining a sense of perspective from their injury, and this generally related to their having an insight into or changing their views on what is important in life: “outlook on life changed,” “I’ve learned to be more realistic about things.” Many people also talked of appreciating life in a new way, realizing how they should make the most of it and how valuable (and short) it is: “I’ve learned to concentrate on things that are still possible and improve them instead of feeling sad about the things that aren’t possible anymore,” “With a lot of courage and will it is still possible, even with a constrictive illness, to live your dreams and practice some beloved activities,” “Life is too short; have as much fun as possible,” “Value every minute of life,” “Realize how beautiful life is; don’t waste time thinking, just do.”

#### ***Changed personality***

“From the day of my injury I have grown into the person I am today.” Many people stated that their personality had grown or developed as a result of their SCI. The theme of an increase in patience was often talked about, as was that of tolerance and caution. Some people felt that their personality had changed such that they were more cautious about things and took fewer risks. Some comments about what people had gained or learned about their personality since SCI included “to be more patient, to open up,” “more open, learned to laugh at myself,” “stronger person,” “able to help others, nicer person,” “grown up, more open minded and grounded.”

#### ***Nothing***

Patients for whom this theme was relevant had written “nothing” on their questionnaire form and felt that they had not yet gained anything from their SCI. Individuals most often gave this response at individual time points; it was rarely written at every time point.

### ***Understanding/perspective of disability/SCI***

“To see and understand this disability with different eyes and a different understanding.” This theme related to a sense of having a new understanding of injury, illness, or disability. It often related to people having a new perspective of others with disabilities and an appreciation of what they had been through and what life was like for them.

### ***Appreciation of relationships***

A commonly raised theme was that of appreciating and being grateful for the role and importance of interpersonal relationships as part of life and the need to value and prioritize these. For example, many people said that they “appreciate support,” “quality not quantity,” and “appreciate family and friends.”

### ***Knowledge of SCI/body***

A number of people referred to having gained an increase in knowledge since their SCI. This was related to several domains: knowledge of SCI was talked about a lot in general, followed by body knowledge (“I have learned to listen to my body,” “getting more aware of bodily functions”). A few people also mentioned that they had gained knowledge about the medical system and general self-knowledge as a result of their SCI.

### ***Relationships***

For a number of people, the psychological experience of being in a relationship, as opposed to appreciating the experience, was a key area in which positive changes were described following their injury. This most often related to having an increased insight into personal relationships; people described that they had “realised who their friends were” or that they had more real friends than they thought. Similarly, one person wrote, “True friends few, but acquaintances many.” People also commented that their relationships with friends or family had become stronger; this was mentioned in a general sense as well as in relation

to specific family members: “close people move even closer together,” “relationships stronger,” “closer to daughter/mum/family/friends.” Some individuals talked about having gained new relationships since their injury, such as with fellow patients or a new group of friends: “I got to know new and nice people. I have a strong company and alliance that I didn’t know before.”

### ***New goals/priorities***

For some people, the experience of SCI had provided an opportunity to re-evaluate their life goals and priorities, and in many cases these changed and altered from prior to the injury: “priorities changed; live for the moment,” “importance of priorities, reassess and pursue goals,” “successfully accomplishing trivial things motivates me to go on,” “I’ve changed my priorities fundamentally and concentrate on the most important things,” “find new things to enjoy.”

### ***Opportunity/challenge***

“I turned my life around.” A small number of respondents said that for them, the SCI represented an opportunity to do something different, representing an “opportunity to change my life,” “challenges and ambition, drive and determination,” “appreciate challenge.” This related to several domains, for example, trying new things (“opportunities to try things, eg, sport – wouldn’t have done otherwise”), ceasing risky behaviors (“I stopped smoking”), work or hobby related (“despite the paralysis there are other possibilities of occupation. For instance, looking for different hobbies, use of the computer without using the hands”), and helping people (“able to help others, permanent fundraiser”).

### ***Acceptance***

A small number of people talked about having gained a feeling of acceptance following their injury. This could have been related to the injury itself (“I try to accept it,” “to accept my body”) or to an acceptance of needing to receive help from others.

### ***Appreciation of health/health care***

Some people commented that they had gained a new appreciation of health following their injury (“health is more important than anything else,” “health is the most valuable thing”), and some also mentioned that they were grateful for health care, for example, “appreciate services and time people give, great GP.”

### ***Spirituality***

When people were asked what they believed they had gained following their experience of SCI, a few individuals talked of a sense of increased spirituality in their lives. This was not always in a religious sense, such as: “faith in God,” “to pray,” but was also spoken about in more general terms, such as “belief in destiny,” “spirituality,” “prayers answered, turned life around.”

### ***New skills***

Some people commented that following SCI they had gained new skills, whether this was related to the SCI, such as “learning how to be independent in a wheelchair,” “learning to inform others what I need myself,” and “coping strategies” or other skills that were not necessarily specific to the SCI, for example, “improved communication skills” and “problem-solving abilities.”

### ***Discussion***

This study aimed to investigate individuals’ perceptions of things they had gained from the experience of SCI. It provides a useful contribution to the literature in the field of positive outcomes following SCI, an area in which there is a paucity of research, and examines the reported experience of people at 4 time points following an SCI. Although we are aware of the challenges people face following injury, it is important to balance these with the perspectives from SCI individuals about the perceived benefits.

The results illustrate that many individuals were able to think of positive benefits following SCI, and these related to a wide range of domains: relationships, appreciation of relationships,

perspective and appreciation of life, new goals or priorities, understanding of SCI or disability, appreciation of health or health care, changed personality, opportunity or challenge, knowledge of SCI or body, newly acquired skills, spirituality, acceptance, and nothing. Overall, the highest percentage of responses related to the theme of perspective/appreciation of life, and many participants also mentioned benefits in relationships generally and in terms of changed personality. The themes that received the fewest responses were spirituality, newly acquired skills, and appreciation of health/health care.

The average numbers of responses according to theme in the present study concur with the findings of Pollard and Kennedy,<sup>7</sup> who used the PTGI to examine perceived benefits after SCI. Of the 5 domains assessed by the PTGI, 3 overlapped with the present findings: relating to others, appreciation of life, and spiritual change. Moreover, in both studies, a large number of responses were based on relationships, and few were related to spirituality.

The results are in line with the broader PTG literature, in which the 3 most typically mentioned areas of positive change following adversity relate to perspective of life, perception of relationships, and perception of self. The most commonly mentioned theme was perspective/appreciation of life; this is an area that was also identified by Chun and Lee<sup>15</sup> in participants’ narratives of their lives after SCI. Individuals in both studies made comments about valuing every minute of life, being more thankful, and appreciating the smaller things. It appears that having a new appreciation of life is an area in which individuals feel that they have benefitted after SCI.

Second, interpersonal relationships appear to be a significant area in which positive gains are perceived after SCI. This was mentioned in the present study as increased strength and closeness in relationships and is well supported by previous research; individuals after SCI have reported feeling greater compassion and closeness toward family members.<sup>14</sup> Interpersonal relationships may be also be important in helping individuals overcome barriers associated with this disability and enable them to pursue meaningful life goals.<sup>16</sup>

There is a need to ascertain relationship factors to help support individuals after SCI.

Experiencing an SCI was seen as a chance by some individuals to change their goals and priorities in life and to find new opportunities and challenges. Many people also felt that they had noticed positive changes in their personality after injury; this was also mentioned in previous research in which individuals felt that they understood themselves better after SCI, had an opportunity for self-improvement, and were able to acquire new skills.<sup>16</sup>

After SCI, many individuals reported that they had an increased sense of empathy for other persons with disabilities, and some expressed a desire to help through fundraising. Previous research has also found that one of the main ways in which individuals with SCI reported using their disability positively was to help others in their community through advocacy and membership in disability-related organizations.<sup>16</sup> This awareness of others with disabilities has also been described in the literature on PTG, where individuals report having greater sympathy and understanding for what others are experiencing following trauma.<sup>23</sup>

Some individuals in the present study reported that they had accrued knowledge about SCI and their body, and this conveyed a sense of feeling more tuned in with their body post injury. A small number of respondents commented that the injury enabled them to turn their life around and stop negative health habits such as cigarette smoking. Similar findings have been reported by McMillen and Cook,<sup>14</sup> who found that individuals with SCI reported consuming less alcohol following injury, and findings by Hefferon and colleagues,<sup>13</sup> who highlighted the general importance attributed to the body and health in individuals experiencing PTG after life-threatening illness. This suggests that following injury, individuals alter risky health behaviors, which could be related to their having a new appreciation of health and life.

Some people reported that they had gained a feeling of acceptance following SCI. This may be an important finding, given that individuals have previously reported that the process of accepting their SCI enabled them to view and

use it positively.<sup>16</sup> Individuals commented that acceptance takes time and reflection and is an ongoing process, but one that enabled their lives to advance after SCI.

A limitation of the present study is the attrition that is inherent in the longitudinal design, although the large initial sample size may have helped to buffer the effects of missing data. Second, the research question may have been interpreted differently by English and German participants. For example, "gained" may have been interpreted as "learned" in German. However, this should not have had a severe impact on the validity of the findings, as both forms of the question ask participants to think about the positive aspects that they have gained from their injury, which was the primary factor under investigation. Also, given the nature of the open-ended question that was used, there is always the limitation of not knowing what participants may have left out in their answers.

Despite these limitations, the current findings have theoretical and clinical implications. They provide a more nuanced understanding of the positive outcomes of SCI, perceived first-hand by affected individuals. In terms of clinical relevance, research into positive outcomes of SCI may provide useful information for newly injured persons to give them a deeper insight into life after SCI. This would be important in all phases of the rehabilitation process, but it may be especially important for persons who are experiencing greater distress and who may benefit from a more realistic view of the range of possibilities for future living. Information from the reports of persons who have lived with the disability is key for this purpose<sup>24</sup> and has been found to be useful to spinal cord-injured persons.<sup>21</sup>

In a therapeutic setting, a deeper knowledge of positive outcomes after SCI may provide clinicians with a more balanced view of outcomes following a major trauma such as SCI. Through the reconstructive process of meaning making in therapy, clinicians can help individuals to identify aspects in their life that may not have changed following SCI or aspects that may have changed but in a positive way (negative consequences that individuals may need to work through should also be acknowledged).

Further research is required to explore opportunities for developing an intervention specifically for the SCI population and to better understand the mediating factors of positive outcomes so that these may be best facilitated in clinical practice.

## Conclusion

Much research has highlighted the negative consequences of SCI. This study has provided some balance by exploring the gains perceived by people after experiencing SCI. These findings are of importance not only to provide information to the newly injured, but also to support clinical interventions. More research is needed to provide a greater insight into the full range of possible outcomes of SCI through

the eyes of those living with this disability, to determine what can account for these changes, and to identify how clinical interventions may be able to facilitate positive psychological progress in people following SCI.

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